DOCUMENT RESUME

ED 188 395 EC 124 355

AUTHOR Schoenherr, Arline; Schnarr, Barbara
TITLE Program for the Chronically Ill.
INSTITUTION Detroit Public Schools, Mich. Dept. of Special Education.
PUB DATE Apr 80
NOTE 27p.; Paper presented at the Annual International Convention of The Council for Exceptional Children (58th, Philadelphia, PA, April, 1980, Session W-27).

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Anemia; Asthma; Diabetes; Elementary Secondary Education; Heart Disorders; *Hospitalized Children; Parent School Relationship; Physical Health; Program Descriptions; Records (Forms); *Special Health Problems; *Teacher Role

ABSTRACT

The program for chronically ill students in the Detroit public schools is described. Forms are presented listing needed information and implications for teachers of the following conditions: diabetes, sickle cell anemia, chronic renal failure, congenital heart disease, hemophilia, rheumatoid arthritis, asthma, leukemia, and cystic fibrosis. The role of the teacher consultant in linking family and school and child and school is examined. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED188395

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

Detroit Public Schools
PROGRAM
FOR THE CHRONICALLY ILL

EC124355

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Arline Schoenbeck
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Department of Special Education

WHO ARE CHRONICALLY ILL CHILDREN?

They are a group of physically or otherwise health impaired children who neither belong in a special school nor require a teacher of the homebound. These are children with such chronic illnesses as cystic fibrosis, sickle cell anemia, rheumatoid arthritis, cancer, brittle diabetes, asthma and hemophilia. These children have frequent, short-term absences from school and are usually doing poor academic work. They often repeat grades and frequently quit school early.

HOW ARE CHRONICALLY ILL CHILDREN IDENTIFIED?

The teachers of the chronically ill visit pediatric wards of the city hospitals, the renal units, onocology, hematology and diabetes, etc., to identify chronically ill students. These teachers may be contacted by social workers, school administrators other teachers and counselors. The Special Education Department may also inform the various agencies; i.e., United Cerebral Palsy, Muscular Dystrophy, Sickle Cell Detection Centers, etc., of this program and request referrals.

WHAT SERVICES ARE PROVIDED TO THE CHRONICALLY ILL?

Educational services to support the regular education program may include individual tutoring as well as administering tests or exams. The teachers often begin working with a child in the hospital setting and continue at home as well as when the child returns to school. The teacher of the chronically ill is truly a home/school/hospital teacher.

SUCCESS OF CHRONICALLY ILL STUDENTS OCCURS WHEN:

- ○ THEY ARE PROPERLY IDENTIFIED
- ○ ADDITIONAL TEACHING SUPPORT IS PROVIDED DURING PERIOD OF ABSENCE
- ○ ADJUSTMENTS IN PHYSICAL ACTIVITIES ARE MADE IN ACCORDANCE WITH STUDENTS' ILLNESS LEVEL
- ○ STUDENTS ARE RECOGNIZED FOR WHAT THEY CAN DO, RATHER THAN BY THEIR LIMITATIONS
- ○ STUDENTS ARE ENCOURAGED TO BE INDEPENDENT AND TO ACCEPT RESPONSIBILITIES.

FOR FURTHER INFORMATION CALL OR WRITE, ARLINE SCHOENHERR, SUPERVISOR OF PHYSICALLY AND OTHERWISE HEALTH IMPAIRED PROGRAM, DETROIT PUBLIC SCHOOLS, 5057 WOODWARD, 494-1669

Detroit Public Schools, historically and in compliance with Michigan Public Act 198 and Federal Public Law 94.142, have a large program for physically or otherwise health impaired (P.O.H.I.) There is a staff of over one hundred teachers seven occupational therapists, six physical therapists, four nurses, thirty special education aides and six administrators.

There is a third group of physically or otherwise health impaired children who neither belong in a special school nor require a teacher of the homebound. These are the children who are chronically ill with such illnesses as cystic fibrosis, sickle cell anemia, rheumatoid arthritis, cancer, brittle diabetes, asthma and hemophilia. These children have frequent, short term absences from school and usually are doing poor academic work. They often repeat grades and frequently quit school at age 16. Special education services began in Detroit for this third group in March of 1978.

The writer of this paper, as a special education supervisor, and Ms. Barbara Schnarr, teacher consultant of the physically or otherwise health impaired, with the encouragement of George Adams, Region Superintendent, began a survey of the need for this service in Detroit. Careful records were kept of calls the special education department received from parents, social workers, or nurses reporting

Arthur Jefferson,
General Superintendent

4

Norman V. Fuqua,
Executive Deputy Superintendent

children who would be absent for one or two weeks whose diagnosis was one of chronic illness.

Ms. Schnarr visted pediatric wards of the city hospitals and spoke to the nurses on the renal units where children were admitted three days of every week for dialysis. Ms. Schnarr also contacted the hospital social workers of the pediatric hospital units for cystic fibrosis, respiratory problems, blood disorders, rheumatoid arthritis, and cancer. A list of names was compiled with the name of the child's school. The schools were contacted through the office and Ms. Schnarr made personal calls to the high schools and continued the hospital contacts. The office also contacted the various agencies (i.e., C.P., M.D., Sickle Cell Detection), informing them of the new program and requesting referrals.

In compliance with Michigan Public Act 198, we sent certified letters notifying parents of our intention to begin educational service for the chronically ill student. An educational planning and placement committee meeting (E.P.P.C.) was held with parents, and we emphasized that Ms. Schnarr represented additional educational assistance, truly a home/school/hospital teacher. The emphasis for locale of teaching has been hospital/school with frequent telephone communiques with parents. Ms. Schnarr began teaching in May of 1978 and the 1978-79 school year. She has office and classroom space at Children's Hospital of Michigan. On October 1, 1979, we added another teacher consultant, Ms. Van Kempen, who has office and classroom space at Mt. Carmel Hospital - Pediatrics.

The teacher consultant often begins working with a student in a hospital setting and would continue when the child goes home, to help

him keep up with his class work. When he returns to school, he may not need the special service for awhile. Later, if there is another flareup of illness, it would be the responsibility of the family to contact the teacher consultant so that she can be immediately in touch with the school. The child might be ready to return to school right after the hospital stay. At that time there might be a need for the teacher consultant to arrange to see the child regularly at school to help him "catch up" to his class with his assignments. Continuation of service would often be dependent upon communication with the family when service is needed.

The individual attention and guidance given the child in this program can be a successful method of providing support to the family of a chronically ill child. Parents are often so involved emotionally in supporting the child at a time of physical need that they are unable to even let the school know how seriously ill a child may be.

The teacher consultant acts as a link between family and school personnel as well as a link between the child and the school. School personnel are often glad to find "one of their own people" available to provide educational service to the child when previous experience were with the parent or hospital personnel providing what service was available. The school can be more specific about the individual needs of the child. They are often able to provide testing material to the consultant which they might hesitate to allow lay persons to administer.

It is hoped that many students who may have contemplated dropping out of school will consider this program an alternative choice. Some older students may wish to study skills which would enable them to take the G.E.D. test after a period of time.

DETROIT PUBLIC SCHOOLS

S P E C I A L E D U C A T I O N D E P A R T M E N T

Principal of_____School

_____is a student whose chronic illness may cause frequent short term absences from school. He/she has been placed in a Special Education Program with a teacher consultant for the chronically ill. The teacher consultant will work with him/her at school to provide individual support in areas of academic weakness and will work with him/her at home or when hospitalized as need.

Chronically ill students can succeed in regular school when:

1. ☐ they are properly identified
2. ☐ additional teaching support is provided during period of absence
3. ☐ adjustments in physical activities are made in accordance with students' illness level
4. ☐ students are recognized for what they can do, rather than by their limitations
5. ☐ students are encouraged to be independent and to accept responsibilties.

The teacher consultant will contact you again regarding this service to be provided. If you have any questions please call me at 494-1669

Sincerely,

Arline Schoenherr, Supervisor
Programs for Physically or
Otherwise Health Impaired

AS/oc

Arthur Jefferson,
General Superintendent

Norman V. Fuqua,
Executive Deputy Superintendent

THE ROLE OF THE TEACHER CONSULTANT FOR CHRONICALLY ILL STUDENTS

A teacher consultant will be regularly available in all Detroit hospitals to investigate referrals of chronically ill children who have had multiple hospital admissions.

A teacher consultant will follow up identification of pupils with patient and parent interview. Parent may be interviewed by telephone at this time.

Teacher consultant will contact the child's school on a regular basis to determine specific educational needs or deficiencies.

Some pupils may be referred by school or attendance personnel.

Contact with school may provide immediate homework assignments to be completed.

Children will be placed in the program by an E.P.P.C.

An Individual Educational Plan will be written for all children to meet specific goals and objectives, both long and short range; goals will be frequently updated.

Pediatricians believe one of the best things they can do for the health of a child is to educate families. We are not doctors, but perhaps in addition to helping a child we may help parents understand the child's chronic illness.

Continuous communication with schools is essential to evaluate and assess progress.

Periodic consultations with hospital personnel will also be beneficial to the child's progress and will alert the consultant to any special problems.

The consultant provides educational as well as emotional support to the student. It is also important that contact be maintained with the family so that they are aware of progress and any emotional problems that may arise.

WHAT THE DIABETIC STUDENT WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Diabetes results from a deficiency of insulin. This lack of insulin prevents utilization of carbohydrates for energy. Children with diabetes must follow a diet and take daily injections of insulin; with few exceptions, they should be treated as other students. The diabetic child's teachers, the principal and/or counselor should know that the child has diabetes.

Teachers need not be unduly concerned about a diabetic child in the classroom, but it is prudent for the teacher to have a conference with the parents to obtain any special information about the diabetes and the particular child. Even with the most diligent compliance, some children's diabetic condition for unexplained reasons is difficult to regulate. This is often referred to as brittle diabetes.

Please in contact with the child will find it helpful to understand the following fundamentals concerning diabetes:

1. Diabetic children do not outgrow their condition. Their need for insulin may increase with age and increasing weight. Children cannot be treated orally; insulin injections are essential for every child.

2. Most diabetic children are required to eat at certain times of the day besides at their three main meals. An afternoon snack between 1 and 3 p.m. is usually required, the exact time depending on the time of the child's lunch.

3. "Reactions" occur when the sugar in the blood is low. While too much insulin often causes such a reaction, commonly referred to as "insulin reaction", this may also be brought on by too little food, a delayed meal, excessive exercise, or a combination of these factors.

4. "Reactions" may occur anytime during the day, but they frequently occur shortly before meals or immediately after strenuous exercise. Some diabetic children take extra food before active periods. If possible, the daily school schedule should be arranged so that strenuous exercise follows rather than precedes mealtime.

5. Children having a "reaction" may experience hunger, excessive perspiration, trembling, inability to concentrate, irritability, dizziness, pallor, crying or confusion. Symptoms of an insulin reaction vary, but it is a safe rule that a course of carbohydrates should be given at once to any diabetic who is behaving inappropriately. Initially, the child may need to be encouraged to eat; however, as their condition improves, they will usually accept food readily.

6. The feeling of being different is a difficult one for diabetic children. They cannot eat lunch at school, go to birthday parties (i.e., candy, fruit juices). Continued support is needed.

WHAT THE CHILD WITH SICKLE CELL ANEMIA WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Sickle cell anemia is an inherited blood disorder found predominately in black children. The transmitted genes of this disease cause a disorder of the oxygen carrying parts of the red cells. Red cells are normally round, but when they begin to sickle, they change from round to elongated shapes. They tend to jam up in small blood vessels and will not pass through the capillaries. Without the oxygen carried by the red cells, tissue dies. This is a painful time for the student.

The second problem with sickle cells is that they do not last as long as normal red blood cells. Normal round red cells live about 120 days. Sickle red cells are more fragile than normal red cells and live for less than 60 days. The body cannot make red blood cells as fast as the sickle cells are being broken down. As a result, the body has fewer red cells and less hemoglobin than normal, and this is called anemia. All of the medical problems in sickle cell anemia are the result of either the plugging

of blood vessels with sickle cells or the anemia.

Individuals who have sickle cell anemia have pain that might occur at any time in any part of the body. The pain might last for only a few minutes or for as long as a week or two. The pain might be relieved by aspirin or might require hospital treatment. The pain occurs when sickle cells plug blood vessels and stop the flow.

Children with sickle cell tend to tire easily as a result of the anemia. They may, however, go to school as other children; their only restriction being non-competitive sports.

WHAT THE CHILD WITH CHRONIC RENAL FAILURE WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Chronic renal failure occurs most often in adolescents who have untreatable nephrosis. Nephrosis is a condition characterized by massive losses of body protein through the urine as a result of kidney damage caused by gross swelling of the body. Control of nephrosis in about 90 percent of children is achieved by steroids and antibiotics; only 10 percent now "progress" to renal failure.

Renal failure means only a few thousand of the millions of nephrons remain in the kidneys to take care of water, salt, chemicals and protein that the boyd takes in. The urine backs up in the blood when the kidnesy can no longer purify the wastes and get rid of them; the result is uremic poisoning. When death is inevitable unless drastic measures are taken, some children are "put on" dialysis or flushing the kidney wastes by artificial means.

This hemodialysis is used while awaiting a kidney transplant from a live donor or a cadaver. Hemodialysis requires surgery to implant a shunt in the arm or groin which is large enought to admit tubinr or one of the arm veins may be enlarged; or a fistula made into which a needle can be inserted. The student must spend three days a week on the machine; his life is dependent on the machine while he awaits a transplant. Even while on the machine, children still are subject to problems caused by uremia. They tend to accumulate salt and water. These children are anemic, fatigue easily, there is growth retardation, and sexual impotence. Additionally, there are severe diet restrictions - low salt, low protein. It is unpalatable and restrictive. Fruits and vetegables that contain potassium are out; i.e., potatos and bananas.

Quality of life is not impressive, yet most choose dialysis, and teenagers who have had successful kidney transplants are happy. These teenagers need tremendous amounts of emotional and practical help. Teachers of the chronically ill work with these children when they undergo dialysis at Children's Hospital of Michigan and may see the student again in his middle school or high school. The excessive absence incurred by their illness requires the help of all the "regular" teachers in assigning lessons and working with the special teacher.

WHAT THE CHILD WITH CONGENITAL HEART DISEASE WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Congenital heart disease is the major cause of heart trouble in children. This term refers to abnormalities of the heart or its great vessels present at birth or occurring immediately after birth. The treatment of congenital heart disease is primarily surgical. Pediatric cardiologists prefer to operate on children age four or five to repair defects and give the child maximum vigor before he begins school. Early surgery may mean less permanent damage to the heart from the abnormal blood flow created by the defect. Those children whose heart problem is inoperable or who have cardiac problems after surgery must be helped to live as comfortably as possible within their physical limitations.

Many children have second and third operations. Add to this the interruption of school attendance caused by illness and it is easy to see why the cardiac child is often behind in school. There is a social deprivation as a result of not being able to play as other children play. The

cardiac child who was always too tired to play or had to rest frequently as a pre-schooler often cannot adopt to his "new self" after successful heart surgery that gives him newfound vigor. The teacher plays a great part in teaching this child to play and work with other children. The teacher of the chronically ill will assist with the child who still must rest often and is too tired to join his peers.

WHAT THE CHILD WITH HEMOPHILIA WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

In hemophilia, a factor present in normal people and concerned with the clotting of the blood is absent. Hemophilia occurs only in boys and is inherited from the mother. The effects of this absence are apparent following injury when, because the normal clotting mechanism is impaired, the patient will continue to bleed. Small superficial wounds will bleed no more than a normal person, because the tissues contract around the breach in the blood vessels. Larger cuts will bleed in exactly the same manner as in a normal person, but, if left alone, the bleeding will often (but not always) continue. Initial treatment is therefore easy - a dressing applied under pressure will temporarily stop the bleeding until hospital treatment can be given.

The most serious forms of bleeding in a hemophiliac are those which involve deep muscles or joints. In a normal person blows and twists sometimes cause rupture of minute blood vessels resulting in bruising; the bruises

are prevented from enlarging partly by the tension of the surrounding tissue and partly by the normal clotting mechanism. In a hemophiliac, it is only when the pressure from the tissues is the same as the pressure exerted by the escaping blood that bleeding will stop. This is why joints become swollen and painful. In the absence of proper treatment, the bleeding takes a long time to resolve, the muscles round the joint become weak, and following repeated episodes, permanent disability can occur.

Treatment of bleeding in hemophiliacs is nowadays quite simple, and only requires an intravenous injection which replaces the missing factor in the blood called Factor 8. This injection is obtained from human blood and may have to be given in the hospital. When bleeding into a deep muscle or joint occurs, the affected limb sometimes needs splinting, but it is rarely necessary to keep the splint on for more than a few days. There is no medical reason why a child should not attend school following all but the most serious injury.

We feel that it is better that children suffering from this disease should require occasional treatment for bleeding, rather than be banned from the normal activities of home and school.

The teacher of the chronically ill child is available to help the classroom teacher accept the child with hemophilia and to correct any misinformation regarding external bleeding or accidents. Teachers need to begin encouraging skills for occupations that include white-collar, technical and clerical jobs, or "light" factory jobs.

WHAT THE CHILD WITH JUVENILE RHEUMATOID ARTHRITIS WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Juvenile rheumatoid arthritis strikes very young children with a wide range of medical and social disability. This disease is characterized by an inflammatory reaction in the cells that line the joints. Home, not hospital, is the major place for care of the child with this long term disease. Prevention of severe crippling is the goal. Unlike other diseases that have crisis with pain, rheumatoid arthritis is a long and continual pain accompanied by depression. The child in severe pain withdraws and is sober and listless. The decrease of pain causes the child's attitude to change abruptly. He is happy and active at home and in school. He is not cured, however, and the disease may become active again at any time; it is a discouraging disease for parent and child.

Treatment consists of large doses of aspirin. Aspirin is <u>not</u> given for pain; it is an anti-inflammatory drug and, of course, as the inflammation subsides so does pain. Like all drugs, however, there are

adverse side effects; i.e., nausea, ringing of ears, stomach pain, and doctors need to be notified. Other medications include gold injections and on rare occasions indocin or steroids such as prednisone or cortisone. Physical therapy is a treatment for rheumatoid arthritic children that is designed to prevent or correct deformities.

The child with rheumatoid arthritis needs rest as well as exercise and often the school age child pushes himself to keep up with his peers and over-exercises. Swimming is the most recommended sport, but all competitive activities are prohibited because of possible trauma to the joints. Only a small percentage of arthritic children have serious crippling; most can attend regular classes. They may suffer considerable fatigue and joint pains and need some special consideration of the teacher at change of class and being allowed extra time to climb stairs.

Children who have arthritis early in life learn to adapt to a quiet style of life. Adolescents who have always been health and then are hit with rheumatoid arthritis need a great deal of support from teachers and friends as well as social workers to modify his activities.

WHAT THE CHILD WITH ASTHMA WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be located	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Asthma is the most common chronic disease of childhood. The child with asthma has serious difficulty in breathing with wheezing, shortness of breat, tightness in the chest, coughing and choking. The lack of breathing ability results from a narrowing of the air passages (bronchial tubes) in the lungs. This can be caused either by muscle spasm, swelling of tissue, too great a release of mucous and dried mucous plugs or a combination of all three. The air passages to the lungs are easliy irritated by various kinds of outside stimulation, such as cold air, strong odors, smoke, certain infections and allergic reactions to inhaled substances.

When a child has asthma the work of breathing is greatly increased. This is brought about by obstruction to the flow of air in the breathing tubes. This causes overdistended lungs - abnormal distribution of inhaled air from the lung.

Typically, an asthma sufferer may feel quite good between attacks. At these times, however, the lung function in severe asthma is rarely completely normal even when there are no symptoms or wheezing. This means that asthma may be present even when the patient is feeling well. If a person has more than six attacks of wheezing a year, he will probably have some asthmatic obstruction even when he is feeling fine. The problem with almost all asthmatics is that part of their body chemistry does not function properly. Because of this, asthma attacks are commonly brought about by allergies or bad reactions to outside substances.

These substances may be inhaled from the air, eaten in foods, or taken in medicines that are used for other illnesses. There is no medical evidence to suggest that states of upset or distress, by themselves, cause asthma. But, in a person who already has asthma, undue emotional stress can contribute to asthma flare-ups. It is important for the child with asthma to lead as "normal" a life as possible - this includes discipline, activities, school attendance and social skills.

The teacher's attitude toward and understanding of asthma may prevent her/him from either acting over-protective or panicking during the child's attack. School has the second most important socializing effect on children; second to home.

WHAT THE CHILD WITH LEUKEMIA WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name _____ Date _____

Parent's Name _____ Parent's Phone Number _____

Alternate Person to call in case of an emergency and parents cannot be reached _____ Alternate Person's Phone Number _____

Physician's Name _____ Physician's Phone Number _____

Leukemia is a malignancy of the blood-forming organs. Abnormal blood cells reproduce and accumulate in the blooded bone marrow. The cause is unknown; it is not inherited, nor catching. In leukemia, abnormal white cells replace bone marrow and appear in the blood. Because of the decrease in red cells, the child is anemic, he bleeds and bruises easily; he picks up infections easily and may have bone pain. Untreated, death occurs in six months but each year cancer research provides new and better treatment against this once incurable disease.

School is vital to these children. It means we are planning for the future. Some parents may feel that since death is so great a possibility, school is unnecessary. But children need the competition and the social interaction with their peers.

The treatment of any cancer is painful and may result in loss of hair (a loss as painful to the adolescent as the disease itself), nausea

and extreme fatigue. The treatment represents many obstacles to regular attendance but the teacher consultant of the chornically ill child may assist both student and teacher in helping the child "keep up" with his classmates. The teachers, with the principal and social worker, may help the class to understand the illness and some of the treatment the child is undergoing. There is some danger to the child with leukemia; he needs to be guarded against infection and being hit or kicked because of the danger of hemorrhage, but all agree the psychological gains outweigh the hazards.

During the acute stages of his disease, the student is hospitalized and home but as he goes into remission he is able to attend school and participate in most normal activities without danger.

WHAT THE CHILD WITH CYSTIC FIBROSIS WANTS YOU TO KNOW

(For the School Cumulative Record Folder)

Child's Name	Date
Parent's Name	Parent's Phone Number
Alternate Person to call in case of an emergency and parents cannot be reached	Alternate Person's Phone Number
Physician's Name	Physician's Phone Number

Cystic fibrosis is a chronic lung impairment. It is a hereditary disorder in which unusuallly thick and sticky mucus interferes with the functioning of the lungs and digestive system. It is entirely a disease of Caucasians. There is no cure and until recently life expectancy was one to three years. With improved treatment, life expectancy is increased and cystic fibrosis children are attending school.

The disease has many ups and downs but until late in the illness the child is relatively well most of the time. Medically, the pancreatic ducts are plugged by mucus, preventing pancreatic enzymes from reaching the intestines to break down fat and protein into an absorbable form. The child has a huge appetite with inadequate weight gain. There is abnormal loss of salt through sweat, but the most serious difficulty is lung involvement. In cystic fibrosis secreted mucus is too thick to be

coughed up easily and one of the body's systems of getting rid of bacteria is destroyed.

Daily treatments for the life of the child include postural drainage and aerosol adminstration of drugs two to four times a day. Frequent meals are necessary and extra salt is encouraged. Family life revolves around this daily treatment and creates many problems. Both child and family are aware of the shortened life expectancy but still the treatment must continue.

School problems revolve around the feeling of being different. The cystic fibrosis child has a foul odor to his stool as a result of undigested fat in the stool and he is embarrassed among his peers. He also has a constant loose cough and the need to spit up mucus. The teachers may want to enlist the aid of the social worker in helping the class to understand this fatal disease.